

**Children's Special Health Services
Family Advisory Council Meeting Minutes
February 25, 2006**

Welcome/Introductions/Announcements:

Tammy welcomed the following individuals to the meeting.

Present from the Family Advisory Council: Cheryl Klee, Twyla Bohl, Lisa Beckman, Donene Feist, Jennifer Restemayer, Carla Peltier, Lori Hanson (phone).

Present from CSHS: Leann Bayman, Tammy Gallup-Millner, Kora Dockter, and Sue Burns.

Guests: Pam Burkes, ND Family to Family Network and Alison Dollar, Department of Public Instruction.

The following announcements were made:

- The Family Connections Conference is scheduled June 14-16, 2006 in Bismarck, ND. Family stipends are usually available. Check out forthcoming conference brochures for more information. In the near future, family organization representatives and CSHS staff should hear whether a proposal submitted for a family support panel presentation at the conference was accepted.
- A Parent Leadership Weekend was held January 20-22, 2006 at Spirit Lake Casino and Resort. Attendees had many positive comments to share and relayed they would like to see future family retreats expand beyond the birth to three population.
- Jennifer Restemayer passed out recognition items in honor of National MPS Awareness Day.
- After the May 2006 meeting, membership terms end for Lisa Beckman, Lori Hanson, Donene Feist, and Cheryl Klee. All four members agreed to another two-year reappointment.

Follow-up from November Meeting:

Minutes from the November 19, 2005 meeting were accepted as written. The CSHS Family Advisory Council Recommendation/Review Summary was addressed. Progress had been made in all recommendations from the November meeting. Kora relayed that media activities will soon be completed related to asthma. A family story has been incorporated and a press release planned. Newsletter articles will also be addressed. Possible publications where newsletter articles could be promoted include Blue Cross Blue Shield, Medicaid, ND Chapter of the American Academy of Pediatrics, ND Medical Association, American Academy of Family Practice, Prairie Rose and other nursing magazines, ND Association of the Disabled, Rural Electric Cooperative magazine, etc.

Updates:

National Update

Tammy reported on the Maternal and Child Health Block Grant budget for FFY 2006. Nationally, Title V funding was reduced from 724 million to 700 million with an additional across the board cut of 1%. Some of the funding cut from the Title V block grant was used to restore funding for other MCHB programs (e.g.) Sickie Cell, Traumatic Brain Injury, universal newborn hearing screening, rural health programs, etc. In North Dakota, a potential reduction of \$62,203 in federal Title V block grant funds is anticipated.

Department of Human Services Update

- Tammy relayed they were recruiting a second time for the MCH Research Analyst (SSDI) position within CSHS.
- DHS conducted stakeholder meetings to get feedback on priority issues for the upcoming biennium. A report summarizing findings is not yet available.
- The Budget Committee on Human Services last met on December 14, 2005. The children with special health care need study was addressed at the tail end of the meeting. Tammy presented information on biennial expenditures/appropriations and on diagnostic and treatment costs by major condition type. Bruce Murry testified on behalf of several advocacy groups encouraging the department to speed up the waiver process and provided some draft waiver language. Mike Schwab distributed testimony on behalf of Family Voices of ND. The next meeting is scheduled for March 9, 2006 where a report has been requested regarding the status of the department's Medicaid waiver to children with extraordinary medical needs. In the interim, Legislative Council staff have contacted Tammy to get contact information from surrounding state's CSHCN programs.
- Tammy relayed that several meetings related to the Medical Needs Task Force have been held. Issues covered in the meetings include:
 - Prevalence study – This study estimates the number of children in the state who are medically fragile and have serious emotional disturbances and will profile their medical care costs.
 - DHS/Region VIII CMS – DHS staff met with Region VIII CMS staff to learn about the revised waiver application process.
 - ND One Stop Grant – Members of the Medical Needs Task Force reviewed a model for providing One Stop services to families whose children have co-occurring conditions (DD and mental illness).
 - DHS Waiver Team – DHS representatives have an opportunity to participate in quarterly meetings to ensure a coordinated approach to waivers within the department.

Health Department Update

Tammy relayed that no family representative from North Dakota was attending the Association of Maternal and Child Health Programs meeting this year.

CSHS Program Reports:

Specialty Care Diagnostic and Treatment Services

Leann shared a sample letter that is now being sent to families from CSHS regarding their upcoming financial review. Now, both county staff and families are being notified about the review date so lapses in coverage can be avoided. She also relayed that regional eligibility staff are requesting presentations on CSHS to increase their knowledge of other assistance programs.

Multidisciplinary Clinics

Sue relayed the new clinic directory was mailed in January to over 2,400 individuals. CSHS has had many calls about Dr. Sobus. With her leaving, there will be gaps in some of the clinics supported by CSHS as well as access issues for children with various disabilities. Families in the state will be giving her a plaque and writing up family stories, which will be put into a book to thank her for the care she provided over the years.

Care Coordination

Kora indicated the new care coordination form was put into use October 1, 2006. She has seen more assessment and better plan interventions than in the past. Sometimes forms need to be returned if they are not fully completed. Staff are encouraging quarterly contacts by the county so they can assess for major changes with families served through the program. State level CSHS staff are encountering very challenging care coordination issues as well.

Public Information

Tammy shared the FY 2006 Public Information Plan with advisory council members. A total of 36 activities have been identified for the year in the following areas: 1) Toll-free number 2) Targeted outreach, information and referral 3) Resource library 4) Education/consultation 5) Marketing, and 6) Systems.

Family Information, Training, & Support Update:

Tammy relayed that in the last five-year needs assessment, it was apparent that families were struggling to get the information they needed to help their child. To try and improve the situation, a Title V performance measure was selected to address this concern. CSHS now measures the percent of activities completed in an annual CSHS Public Information Services plan. An activity identified in the current year's plan was to coordinate with family organizations to determine effectiveness of information and referral efforts supported by CSHS. To help with this effort, family organizations receiving CSHS support were asked to report on their funded grant activities.

Pam Burkes provided everyone with a folder of information and indicated that the ND Family to Family Network is part of the Center for Rural Health. The network was started after a parent addressed parent-to-parent support as part of her thesis. Part of the network's focus is peer mentorship where trained (veteran) families are matched with other families. Originally, the match program was designed for an eight-week period. A new need has emerged where "match" support is provided at the time of intake. Network staff are also surveying veteran families to see if matches can be made by topic rather than type of disability. The network also provides information and training for both families and professionals. Five grants, Part C, DPI, CSHS, Bremer, and the DD Council fund Family to Family. Some of the goals for the CSHS grant are support for the advisory board which meets twice each year, the 1-800 number, the database used to track and match, and the website which is used for outreach. Family to Family is also collaborating in the medical home partnership with CSHS. If Family Advisory Council members are interested in regional leadership activities, they can contact Pam for more information. The network now has 201 trained families, 75 referred in the last year. The Family Ties Newsletter is disseminated twice each year and over 2,400 are included on the Family to Family Network listserv. The family to Family Network partners with others as well (e.g.) faith-based initiatives, DPI, Family Connections Conference planning, etc.

Donene Feist, with Family Voices of North Dakota, passed out a CD containing current resources available through the health information center. Family Voices receives funding from CSHS and a CMS grant. A report entitled *Family Voices of North Dakota – Health Information and Education Center* was reviewed. The report summarized data covering the period July 2004 through June 2005. FVND is an important source of information and support for families and professionals. In the last year, information about health care financing was the most frequent request. Information about available resources was also needed. Family Voices reaches a wide

variety of people through meetings, websites, listservs, newsletters, and handouts. Donene relayed calls she receives are taking longer and cover some difficult issues. 50% of calls are from “new” callers. A Dbase is used to for tracking and follows the six core outcomes in the President’s Freedom Initiative. Donene also conducts a survey to assess whether services were helpful and to identify emerging issues. Family Voices conducts trainings and participates in some CSHS clinics as a family support partner. Continued attendance at the annual clinic coordinator meeting organized by CSHS is recommended to foster networking opportunities with families.

CSHS Systems Reports:

Champions for Progress

Sue gave an update Champions for Progress activities. A team attended a meeting in September in Utah focusing on medical home and transition planning. CSHS, Family Voices, and the Family to Family Network jointly applied for an incentive award, which was not received due to federal cuts. Sue passed out samples of Focus on Progress fact sheets. She relayed a similar sheet will be developed for ND and asked for advice on what to include in the following areas:

- Special projects: promote metabolic screening, medical home (Catch grant & training activities), and transition
- Community snapshot: use a family story (Jennifer and Twyla volunteered) or a clinic story
- Useful ND websites/links: include family organization and CSHS websites and link to Head Start, Infant Development, AAP, NDAD, Attorney Generals office, Insurance Commissioner, DPI, Slaits survey data, etc. Check Head Start directory for other websites. Also explore 211 line.

Integrated Services Grant

Tammy relayed that ND opted not to apply for the Integrated Services Grant in partnership with UND and MSU. Donene relayed she was a grant reviewer.

Early Hearing Detection & Intervention

Sue relayed that two new grants were received which will support newborn hearing screening, diagnosis, and follow-up. A summit was recently held with early intervention staff, audiologists, and hospital personnel in attendance. It was decided that children who don’t pass screening would be referred to Right Track. These staff will also receive referrals on “high risk” infants so they can be checked every six months until they are age three. Referrals will be made to the Parent Infant Program for children that need a diagnostic exam. The grant management team is also working on getting others access to the web-based tracking system. The EHDI program recently underwent a HRSA Performance Review which included on site visits, data review, and action plan development.

Transition

Kora shared a copy of transition materials mailed to over 350 CSHS families in September 2005. The plan for this year’s mailing is to include information on the Youth Disability Leadership Conference in Minot which will be held June 20-22, 2006 for youth aged 15-21, the Transition conference which will be held October 2006, and the transition care notebook from Family Voices. DPI agreed to add a health related question to their transition follow-up survey. It will likely focus on availability of insurance coverage. Kora participated in a national meeting with representatives from DPI and Vocational Rehabilitation and is involved in transition planning activities.

Medical Home

North Dakota is partnering with the state of MN on medical home training. A state leadership team will attend a training event in April 2006 and report on the experience to the ND Chapter of the American Academy of Pediatrics in May 2006. After that, formation of a Medical Home Steering Council is planned. The five-year goal for CSHS is to have medical homes implemented in 4-11 practices across the state. More information on medical homes is available on the following website: www.medicalhomeinfo.org.

Open Forum:

This agenda item was held over for a future meeting.

Next Meeting: Saturday, May 20, 2006 from 1:00 – 4:00 p.m.